

## **SPINAL CORD INJURY PROJECT FOR PAKISTAN EARTHQUAKE REHABILITATION (SCIPPER)**

### **Report on Current Conditions of Sponsored Individuals**

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Internee HF Health Programme  
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Special thanks are due to the SCI beneficiaries of the program who shared information and their experiences. The cooperation extended by Ms. Farah Butt, who works as a volunteer in this program, has been very helpful in learning about issues of SCI patients.

In the end, I dedicate this report to the sponsors of this program who made it possible to give life to the destitute and the ones who otherwise would have lost belief in life.

**Rakhshinda Bano**  
HF Health Program

## **1.0. Executive Summary:**

After the great disaster of October 2005, many international organizations came to work for the rehabilitation of the earthquake stricken people. The Spinal Cord Injury Project for Pakistan Earth Quake Rehabilitation (SCIPPER) in collaboration with Hashoo Foundation (HF) aimed at providing services to spinal cord injury (SCI) patients made a better position in this context. The HF surveyed the affected areas and ensured the effective targeting. SCIPPER and HF is working for the last four years for the rehabilitation of the affected survivors.

The purpose of this report is to find out how much the project (SCIPPER) has proved to be successful in achieving its goal and objectives. The major target areas of the report include the general profile of each patient, health status and economic condition before and after the support.

The gender ratio of the beneficiaries is found to be 64:36, comprising of 64% females and 36% of males and the major affected included women and children who belong to all age groups ranging <10 to above 60 years. In aggregate, 53.3% of the beneficiaries evidenced their conditions to be improved as result of this support while only 20% could not improve, rather their condition has aggravated. Other than the financial support, the organization has provided educational and vocational training, caregiver services and equipment for mobility (wheel chair, canes). One wheel chair friendly home has been successfully built and the patient and her family have moved in it and another one has been partially completed. There are considerations in the program for other needy respondents as well.

Few SCI children are also supported for their educational expenses, which can be a long-term investment and requires long-term commitment on the part of donors.

Although all the beneficiaries are satisfied and happy with the financial assistance provided by SCIPPER, however, those families who totally depend on this support are facing problems regarding their food, transport and medical expenses. Moreover, the rugged terrains and environmental conditions of the affected areas are major barriers in their rehabilitation.

## **2.0. Background:**

The devastating earthquake of 2005 brought lot many damages to the inhabitants of Azad Kashmir and NWFP. Besides casualties, a significant number of disabilities were observed after the earthquake. Spinal cord injury (SCI) was one of such disability, which occurred throughout the area. According to

various sources of information, over 700 SCI patients were identified which included mostly women and children.

Major SCI patients also developed cauda-equina and adjacent vertebral and soft tissue damage. Some of them got timely treatment and care however; a few could not receive any medical support thus survived as cervical (neck) SCI patients. Patients survived with varying degrees of paralysis of both their legs (paraplegia) as well as urine and stool incontinence, in addition to the severe psychosocial trauma they experienced.

Those of the hospitalized patients who got fairly good treatment and medication evidenced improving conditions while of SCI patients who returned to shelters and tents in their native villages were not lucky enough to enjoy suitable living conditions.

Moreover, in the remote and inaccessible far flung valleys, there are probable SCI survivors who are yet to be accessed, registered and documented.

## **2.1. First Initiative Towards The Rehabilitation Of SCI Patients:**

Notwithstanding the fact that the earthquake shattered over 1500 km<sup>2</sup> of the region and caused destruction of all the infrastructure including hospitals, health units and all means of communication, majority of these SCI patients were provided with varying degrees of attention, treatment, care and other types of support. Majority of these were transferred to Islamabad, Peshawar, Rawalpindi and other private hospitals of different cities.

## **2.2. SCIPPER Project:**

Responding to challenges of the aftermath of earthquake, governmental and non-governmental organizations and individuals came to the affected area and started rehabilitation initiatives. Dr. Zeba Vanek, Dr. Sofia Janjua and Susan Escueta, from the USA, conducted a survey and collaborated with Hashoo Foundation to start a pilot project, initially for ten SCI patients for their rehabilitation and support. This program aimed at providing educational and vocational training, peer-counseling,

caregiver services, mobility equipment and bladder care supplies like catheters, the goal being to facilitate their basic and medical needs and move towards learning skills that would help them achieve maximum autonomy in their lives.

Dr. Sara Jeewanji, Komal Iqbal and Sana Saharwardhey students from US Universities and Kamila Jeevanji and Tahere Shirazee visited the SCI patients in the affected areas. They helped put together case studies of additional SCI patients in the affected areas and helped raise funds for these patients. Generous donors from the USA and other countries have been regularly sending financial assistance with book-keeping done by Ruqaiya Umarji. These funds are delivered and disbursed by the Hashoo Foundation team and field staff in Pakistan.

This financial assistance is meant for the basic necessities i.e. food, hiring a caregiver, medications, education and training etc.

In a separate initiative, SCIPPER collaborated with CHAL (a philanthropic network run in Pakistan by Haamid Jaffer), PIPOS (Pakistan Institute of Prosthetics and Orthotics run by Dr. Bakht Sarwar), Real Medicine Foundation (a Los Angeles based non-profit run by Dr. Martina Fuchs) and Relief International (a non-profit based in Santa Barbara and facilitated by Mr. Brett Williams) and donor funds were delivered to run a rehabilitation clinic in the remote Balakot area for the spinal cord injury patients.

### **3.0. Objectives Of The Report:**

- Assess the health and well being of spinal cord injury patients living at home.
- Assess the environmental conditions and rehabilitation of the SCI patients.
- To evaluate the overall socio-economic impact of this support, on the lives of the beneficiaries.

### **4.0. Methodology:**

#### **4.1. Primary data:**

- **Discussions:**

Discussions were made with the patients as well as their relatives regarding the major problems they were facing.

- **Questionnaires:**

Semi Structured Questionnaires were made, for both the quantitative as well as the qualitative impact analysis. Interviews were taken, both directly from the patients and from the relatives of the patients.

- **Field visits**

Field visits of NIH-D Islamabad, Balakot, Bagh, Peshawar and Muzafferabad were conducted, for assessing the health status of the SCI patients and the environmental conditions of the areas, they were residing in.

#### **4.2. Secondary data:**

- **Report**

SCIPPER- previous Reports were consulted for assessing the status of SCI patients during the last two years and the extent of overall improvements made in these years.

- **Website**

<http://www.hashoofoundation.org> was visited for gathering information about the stakeholders, background, goals and objectives of the SCIPPER project.

#### **4.3. Selection of respondents:**

There are 33 patients who have been sponsored through this project, however, for the time available; only 30 patients were selected on simple random basis. These patients were interviewed for assessing the impact of support on their lives. The list of the patients is attached as annex-1.

#### **5.0. SCIPPER Project Targets and Goals Achieved:**

- **Number of beneficiaries:**

The SCIPPER project was started with ten patients. But now it has extended its sponsorship to 33 male and female SCI patients of all ages.

- **Funds:**

The funds allocated to each patient are 6000 rupees for each month and Hashoo Foundation has been success full in providing these funds regularly to each patient.

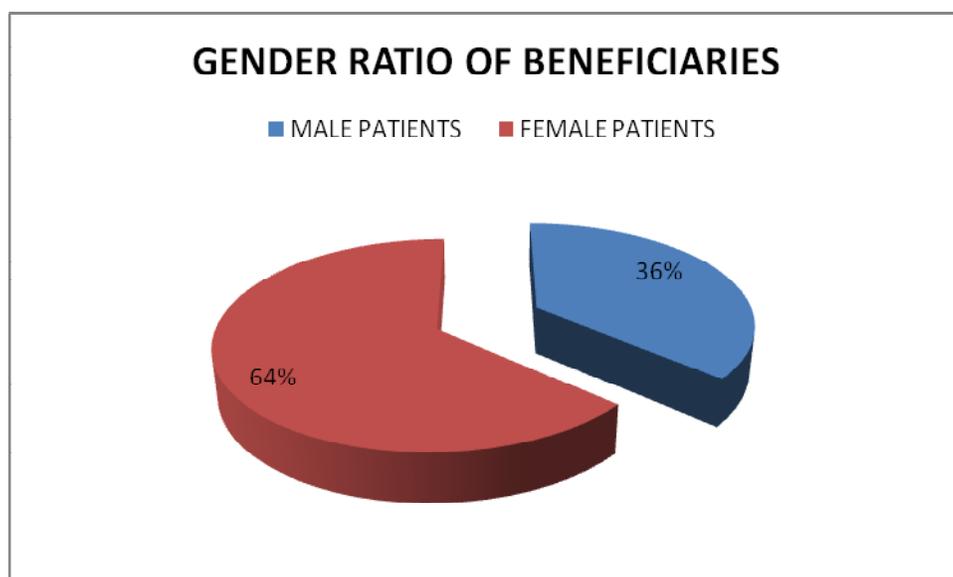
One patient Kausar Parveen has been provided an additional, rupees thirty thousand (Rs.30,000) by her sponsor for building her house.

➤ **Medicines and other aid:**

Medicines have been provided to patients. Mohammad Rafiq, a patient has been given a buffalo as a form of sustainable livelihood, by his generous donor in addition to the monthly financial sponsorship.

## 6.0. FINDINGS OF THE REPORT:

### 6.1. GENDER RATIO:



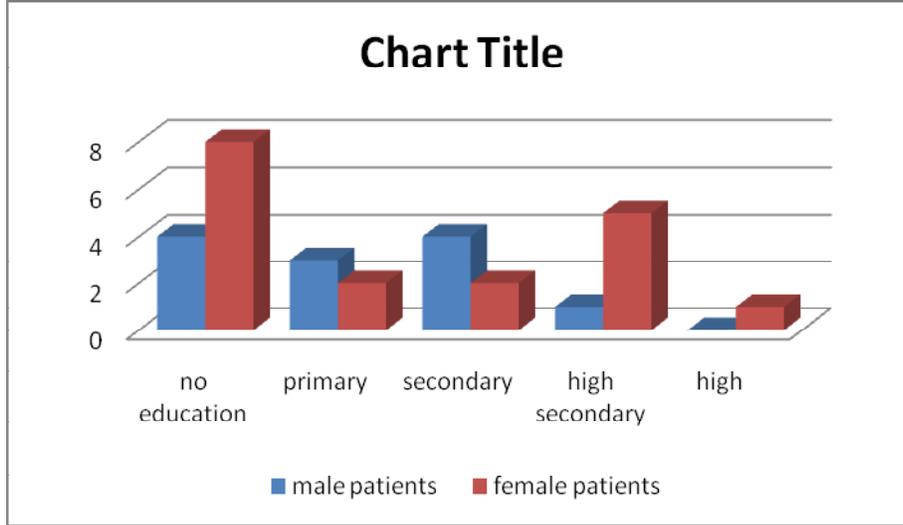
The respondents of the study have a gender ratio of 36:64, i.e., over one-third of males and two-third females.

## 6.2. AGE GROUP OF SCI PATIENTS

Age (years)	Male patients	Female patients	Total
Less than 10	0	1	1
11>20	5	4	9
21>30	3	11	14
30>50	3	5	8
Above 50	1	0	1

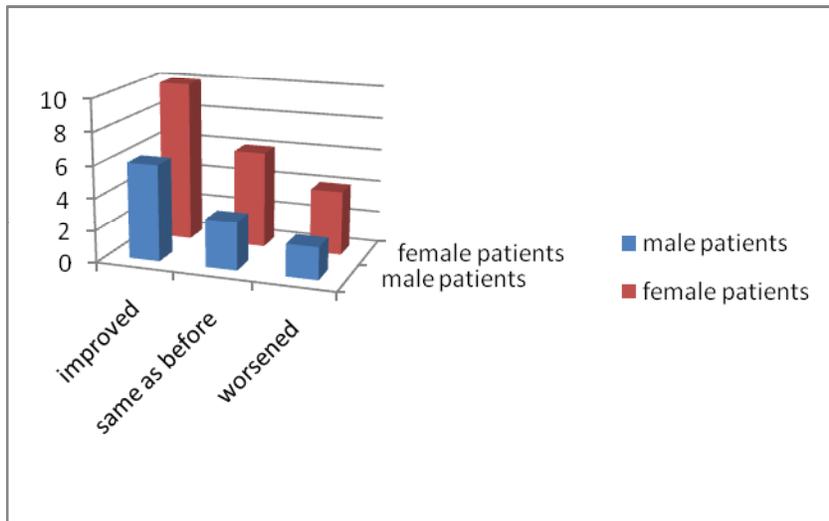
The majority of the patients, 14 (46%) are in the age group 21-30

### 6.3. LITERACY RATIO OF SCI PATIENTS:



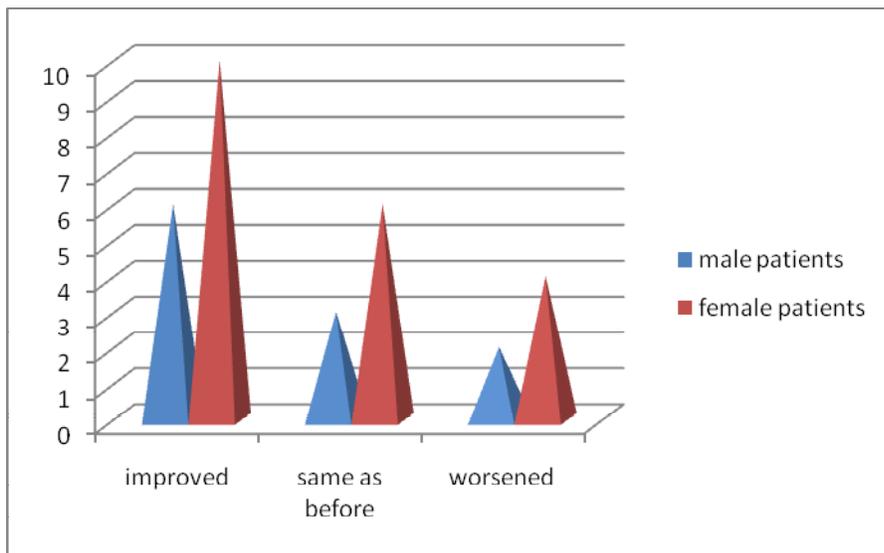
The majority of the patients had not received any formal education.

### 6.4. PERIOD OF ASSISTANCE:



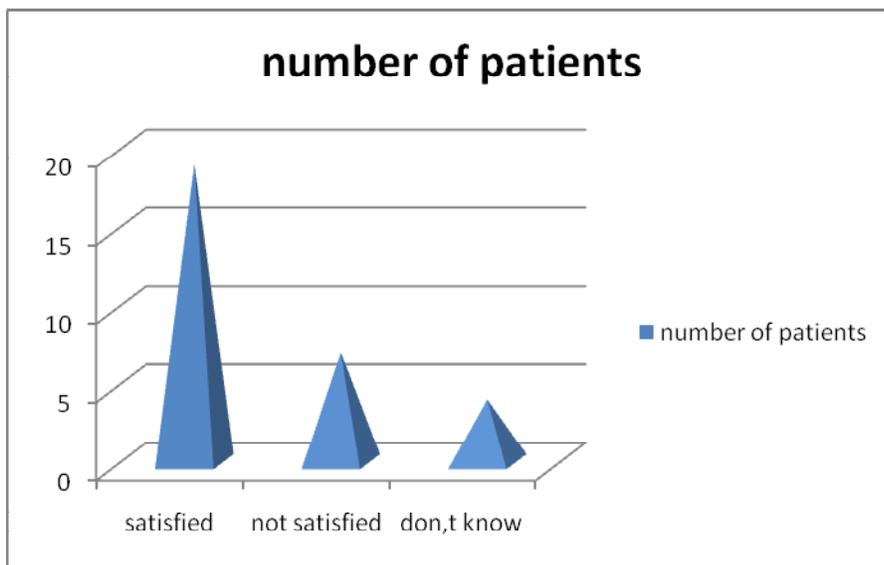
The majority of the females have received assistance during the first three years of the project. More females have been receiving assistance for more than 3 years as compared to males.

### 6.5. IMPACT OF SUPPORT ON PATIENTS LIVES:



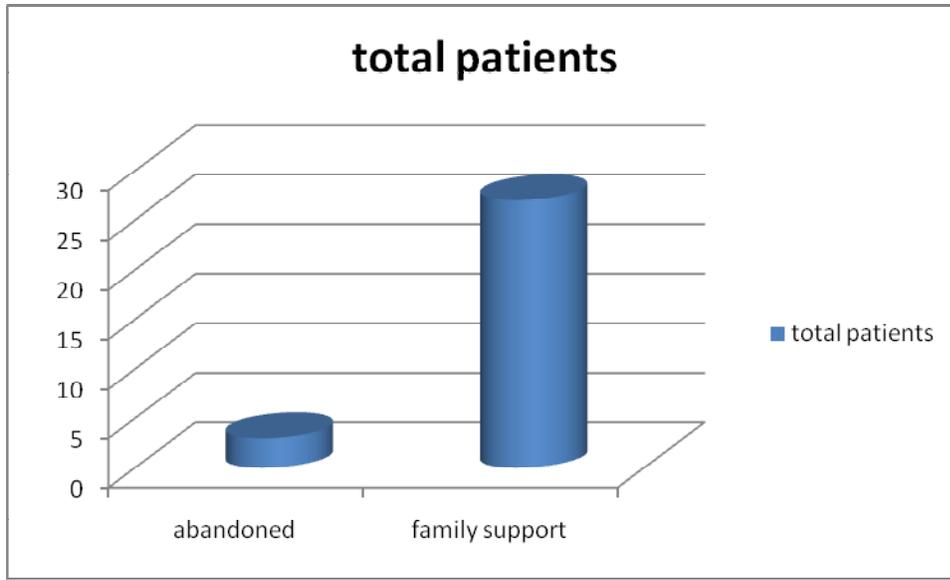
Majority of patients (53%) have shown improvement in their health and over all living conditions. While among females, this ratio is even better, i.e. 56%.

#### 6.6. SATISFACTION OF SUPPORT:



63% of patients were satisfied with the support. However, over one-fifth of the respondents expressed dissatisfaction, mentioning lack of finances and material support.

#### 6.7. SOCIAL CONDITION OF SCI PATIENTS:



10% of the patients have been abandoned by their families. Majority of the patients are still being supported by their families. These 10% abandoned respondents are in dire need of attention and continuous support.

#### 6.8. EXPECTATIONS OF RESPONDENTS:

Support	No of patients
Continue funding	7
Technical assistance	4
Jobs/ business	8
Residence/ Disabled friendly homes	9
Educational support	4
Wheel chairs /medicines/K.F.Os	2

The table reveals that 30% of the respondents expect that, the program should support them with disabled friendly homes type residence.

23% of patients is not expecting any discontinuation of support from the program, as they belong to the lowest income group.

27% of the respondents were looking for jobs and business support as they feel that, they can become self sustained.

## **7.0. Recommendations:**

### **➤ Raise more funds:**

The SCIPPER/ HF needs to raise more funds as the current amount being provided is not enough to cover the basic needs of the patients.

For some patients, this fund is the only source of income for the whole family as the SCIP's are confined mostly in their homes and family members have become caregivers.

### **➤ Help in acquiring jobs and economic activities:**

Since, the patients are out of job mainly for lack of skills; the SCIPPER/ HF can help them and their family members in getting a job and generating an income.

### **➤ Provide vocational training:**

Most of the patients are paraplegics and can utilize their skills to earn for themselves so they should be provided with vocational training, enabling them to earn.

### **➤ Continue funding:**

Some of the patients are young and have attendants who can't leave them to work These would need continuing assistance.

### **➤ Provide new wheel chairs:**

The wheel chairs given to the patients 4 years ago are not in good condition now and most of the patients have become restricted to their beds. They need to be provided with new wheel chairs.

### **➤ Disabled friendly homes:**

Many SCI patients have been evicted by force from hospitals and paraplegic centers by government. For examples more than 100 SCI patients were put on the street from CGH paraplegic center, Rawalpindi by the local police in order to get the place vacated from these SCI patients. These patients are now exposed to unbearable hot weather in their villages and have no proper shelter. They are left with small shelters/tents, which are not wheel chair friendly. These patients appropriate housing.

➤ **Bio-gas facility/technology:**

Azad Kashmir has harsh weather, which causes many difficulties and hardships for the SCIPs. They don't have easy access to fuel wood for cooking and heating, especially in winters. They develop illness from the extreme cold, like pneumonia. They need gas and other forms of heating in winter.

➤ **Transport facility:**

Patients residing in highly rugged terrains need transportation so that they can go for their routine checkups. Conversely, or this could be provided to them by home health workers.

➤ **Counseling:**

Having lost so much, including their mobility, independence and their ability to earn, most of the patients are suffering from depression. Earlier, HF had arranged a team of psychologists for their counseling but with passage of time, it became difficult for them to visit the patients regularly. So this problem can be met by training their family members to provide patients with counseling.

➤ **Improve sanitation system:**

➤ The areas where tents have been put up lack a proper sanitation system, which has led to the spread of diseases and especially in the women. The sanitation facilities in the areas need to be improved.

➤ **Educational support:**

Some patients are continuing their education, with home schooling. They are interested further learning especially computer skills.

## 8.0. ANNEX.1. LIST OF TOTAL BENEFICIARIES

No	Name of SCI patient	Age	Injury	Location
1	Awais Rehman	16	Paraplegic	Balakot, Mansehra
2	Mian Rafiq	18	Paraplegic	Balakot, Mansehra
3	Kaleem-ullah	12	Paraplegic	Balakot, Mansehra
4	Anzar Bibi	20	Quadriplegic	Muzaffarabad Kashmir
5	Shaheen Akhter	29	Quadriplegic	Bagh, Azad Kashmir
6	Wahab Jan	31	Paralyzed	Muzaffarabad Kashmir
7	Anusha	7	Paraplegic	Muzaffarabad Kashmir
8	Khan Muhammad	61	Paraplegic	Bagh, Azad Kashmir
9	M.Hussain Awan	26	Paralyzed	Muzaffarabad Kashmir
10	Ghulam Murtaza	27	Paralyzed	Besham
11	Amir Shehzad	22	Paralyzed	Mansehra
12	Safia Begum	19	Paralyzed	Abbottabad
13	Kalsoom Bibi	36	Paraplegic	Mansehra main city
14	Naseema Bibi	27	Paraplegic	Balakot, Mansehra
15	Bushra Bashir	22	Paraplegic	Muzaffarabad Kashmir
16	Kausar Parveen	27	Paraplegic	Azad Kashmir
17	Salma Akhtar	23	Paraplegic	NIHD-D ISLAMABAD
18	Zubeina	20	Paraplegic	Muzaffarabad

				Kashmir
19	Muhammad Ali Butt	34	Paraplegic	Muzaffarabad Kashmir
20	Chowdry Mangi	37	Paraplegic	Muzaffarabad Kashmir
21	Muhammad Tanveer	18	Paraplegic	Muzaffarabad Kashmir
22	Zahida Kausar	29	Paralyzed	NIHD-D ISLAMABAD
23	Arshad Bibi	32	Paralyzed	Tariqabad Azad Kashmir
24	Rubina Kausar	22	Paraplegic	Muzaffarabad Kashmir
25	Ms.Zahida Parveen	25	Paralyzed	NIHD-D ISLAMABAD
26	M.Kabir Awan	18	Paralyzed	Muzaffarabad Kashmir
27	Ashraf Bibi	36	Paraplegic	NIHD-D ISLAMABAD
28	M.Basir	46	Paraplegic	Muzaffarabad Kashmir
29	Farida jan	29	Paraplegic	Rawalakot Azad Kashmir
30	Rubina Bibi	34	Paralyzed	NIHD-D ISLAMABAD
31	Sadia Noor	19	Paralyzed	Bagh Azad Kashmir
32	Saira Ismail	17	Paraplegic	Muzaffarabad Kashmir
33	Noor Jahan	34	Quadriplegic	4KM away from Mansehra

## ANNEX.2.Detailed Assessment Of SCI Patients

Spinal Cord Injury Project for Pakistan Earthquake Rehabilitation (SCIPPER) has supported 33 Spinal Cord Injury (SCI) survivors by providing them monthly assistance of Rs. 6,000.

The following is a summary of the current status of individual patients.

### **8.1. Rubina Bibi:**

Rubina is from Deer Kot, Bagh. She has been admitted in NIH-D, Islamabad for the last four years and is still there with her husband and three children. She is 34 years old and a paraplegic.

**Health status:** The nature of her injury is fractured lumbar vertebra. Moreover she is suffering from bed-sores of third grade, i.e. bone deep and she has already been operated upon twice. She has a wheelchair and is using external catheters. She is having periodic checkups but no psychological counseling or any physiotherapy. **Environmental status:** Rubina is unhappy living in heat of the Islamabad hospital. She wants to get discharged but also does not want to go back to Kashmir as it won't be possible for Rubina to survive in that rough terrain.

**Economic status:** She feels the monthly sponsorship amount is not enough to support the whole family. She wants HF to help her husband in getting a job so that they could earn a living by themselves and find a residence. She needs these funds till her wounds get healed and her husband gets a job and wants to leave the hospital as soon as possible.

### **8.2. Salma Akhter:**

Twenty-three years old Salma is from Deer Kot, Bagh. She studied till 9<sup>th</sup> grade and was employed as a teacher in a nearby Madrasa. She became a paraplegic after the earthquake and has been abandoned by her family. She is hospitalized in NIH-D since 2005.

**Health status:** Salma's injury is fracture of the first lumbar vertebra. She is having severe back pain and has bedsores. She has had 3 surgeries. She has a wheel chair, which is not in a good condition. She is

using external catheters. Salma is undergoing periodic checkups, but is not receiving counseling and physiotherapy.

**Environmental status:** Salma desperately wants to leave the hospital.

**Economic status:** Salma has been abandoned by her family. But she wants her own residence and wants to get vocational training to earn on her own. She was a religious education teacher and would like to work again as a teacher.

### **8.3. Zahida Kausar:**

Zahida, wife of Ghulam Hussain is from Raj Pothi, Muzaffarabad. She is 25 years old and got paralyzed. Her 2 years old daughter and husband are staying with her in hospital since she got hospitalized.

**Health status:** She sustained a fracture of the first lumbar vertebra and got admitted in 2005. Zahida is suffering from 3<sup>rd</sup> degree bedsores and back pain. She became pregnant during her injury. She has also undergone operations for her bedsores. She has been provided with a wheel chair and is using an internal catheter.

**Environmental status:** The hot weather of Islamabad is unbearable for Zahida and she is unhappy about the not receiving proper cleansing by the hospital staff.

**Economic status:** Zahida is being sponsored for the last three years. She uses the donor funds for food and medical expenses. Zahida would also like to leave the hospital and live in Islamabad.

### **8.4. Zahida Parveen:**

Zahida Parveen is from Dul, Bagh, AJK. She did her matriculation and was working as a teacher in a local madrasa before the earthquake. She is 25 years old and sponsored for the last 2 years. She is still admitted in NIH-D.

**Health status:** She sustained a fracture of the lumbar 3<sup>rd</sup> and 4<sup>th</sup> vertebra. In addition, her left leg has been amputated. She is regularly using medicines and a wheelchair has been given to her. She is using toilet seat, diapers and external catheters.

**Environmental status:** Zahida wants to leave the hospital and finds the environment monotonous and unhygienic and the staff unkind and unfriendly.

**Economic status:** SCIPPER has sponsored Zahida since 2007, which helps cover medical and food expenses. It is the only source of income for the whole family as no family member is employed. Zahida wants to live in Islamabad and wants HF to help her in getting vocational training so that she could earn a living.

### **8.5. Ashraf Bibi:**

Ashraf Bibi belongs to Rawalakot, Kashmir. She is 36 years old and is a paraplegic and also had polio. She has been abandoned by her family.

**Health status:** Ashraf Bibi feels that she has improved in these four years. She would like to work in a women's rehabilitation centre. She has a wheelchair but is not getting counseling and physiotherapy.

**Environmental status:** Ashraf Bibi also wants to leave the hospital.

**Economic status:** SCIPPER is the only source of assistance for Ashraf Bibi for the last 2 years. The funding helps meet her basic needs. She is looking for further assistance in the form of residence and a job suitable for her.

### **8.6. Ghulam Murtaza:**

27 years old Gulam Murtaza is from Batgram, NWFP. He got paralyzed and was hospitalized for 2 yrs. He has been discharged and is living with his wife and brother. His mother, Zer-Jo-Bibi died 6 months after the earthquake from her injuries.

**Health status:** He sustained a thoracic vertebra 7 fracture and is also suffering from bed sores. He has been operated upon twice.

**Environmental status:** the weather is harsh in his mountain home especially in winters. It is very difficult to get wood for heating and cooking. A wheelchair is nearly impossible to use in the uneven hilly terrain.

**Economic status:** Ghulam Murtaza's family was poor before the earthquake. He worked as a laborer. Now they are left without any income other than the funds provided by the SCIPPER donors. The area is remote and there is no means of transportation and communication. Murtaza is taken on a charpai to the main road, which takes two hours. After that they need to hire a special vehicle to take him to the hospital and this costs more than three thousand rupees (Rs. 3000). Murtaza is looking for any vocational training so that he could improve his economic condition as his son is too young to work.

### **8.7. Kausar Parveen:**

Kausar is a paraplegic and is back in her village now. She has been sponsored by SCIPPER for the last three years. Her husband (Kraz Khan) was working in Karachi.

**Health status:** She has a SCI at T12. Kausar goes for medical checkups every 2 months. Her husband helps her in her physiotherapy. Kausar thinks her condition has improved to some extent.

**Environmental status:** They have built their shelter by using sack pieces. Kausar is facing severe hardships as she cannot use a wheel chair in her shelter and is not protected in harsh weather conditions.

**Economic status:** Kraz Khan, Kausar's husband now drives a local public transport vehicle. They need funds for their children's education, food and clothing. His mother (mother in law of Kausar Parveen) has blood cancer and also needs medicines and routine checkups. Ms. Tehmina, her sponsor sent an additional Rs. 30,000 for building her house. And this was given to Kausar in July 2009. She sent more funds for Kausar for Eid. They would need further assistance to build a disabled friendly home.

### **8.8. Chaudry Mangi:**

Mangi belongs to Gari Dopata, Muzaffarabad. He is 37 years old and became injured during the earthquake the day after he came back to Kashmir to meet his family. He worked as a street vendor in Karachi. He was admitted in AFIRM (Armed Forces Institute of Rehabilitation Medicine), later he was shifted to CGH Islamabad. He was evicted with other patients from the hospital.

**Health status:** He is a paraplegic. He has a wheel chair and uses foot orthoses but cannot go for checkups and counseling. He is suffering from back pain currently.

**Environmental status:** He was living in a tent and the terrain is mountainous, rough and rocky and he has great difficulty in using his wheel chair. He also needs a wheelchair adapted home. Moreover the sanitation in the area needs to be improved.

**Economic status:** Mangi's home has a single room, built with corrugated sheets. There is no toilet. His wife is his caregiver and they have two young sons. Mangi has been sponsored for the last two years. He needs more funds, as they are not enough to cover his living expenses. Most of all he needs support to build a disabled friendly home. He wants Hashoo Foundation to support him to start a small business.

## **8.9. Mohammad Kabir:**

M. Kabir is eighteen years old and is paralyzed. He is from Gari Dopata, Muzaffarabad. He was admitted in NIHD Islamabad and was discharged five months ago. He is back in his village and living with his family. He is very thankful to Dr Afshan for her sponsorship. Dr Afshan also started his education and he was promoted to the next class this year. He was provided books, stationary and sports items (Cricket Kit) by Dr Afshan. She is supporting him through SCIPPER since 2008. Tanveer Sikander, patient's elder brother is the only employed person in the family and earns about 100 rupees per day.

**Health status:** patient is suffering from bedsores grade 1(skin) and has also been operated once. He is using medicines regularly and has been provided a wheel chair which is not in a good condition. The patient is regularly using diapers and has gone for medical checkup only once after being discharged. He developed Hepatitis A and acute appendicitis when he was hospitalized and operated upon.

**Economic status:** the economic condition of the family is not good as a single person is supporting the whole family, comprising of 13 members. The funds provided by SCIPPER hardly cover the patient's medical expenses. His diapers cost rupees 1000 per month. Moreover they now need to spend 3000 rupees every time they take the patient to the hospital for his checkups.

**Environmental status** the house the patient is living in comprises of two rooms, which they use both as a kitchen and bedroom, and there is no toilet. Sanitary conditions are deteriorating in the area.

**Impact of assistance:** the sponsorship helps cover medical, food and transportation costs to some extent. He also wants to continue his education again. It is very difficult to find him a qualified teacher in

his village to start his home schooling. Once HF finds a qualified person, more funds will be needed to pay for this.

### **8.10. Mohammad Tanveer:**

Tanveer is from Bagh, Azad Kashmir. He is eighteen years old and is paralyzed. He was hospitalized for a long time and finally got discharged four months ago, when the government asked him to leave as they had no more funds to run the hospital. He is getting assistance from SCIPPER for the last 3 years.

**Health status:** Tanveer is suffering from superficial bedsores. He has been operated upon 5 times. He has a wheel chair but it is not working properly. The patient is using internal urinary catheters and develops recurrent urine infections. He goes for checkups but does not receive counseling and physiotherapy.

**Environmental status:** Tanveer is living in a tent made of steel sheets, which has two rooms. No toilet. During the last harsh winter he developed pneumonia. As the area does not have a gas line the family needs to purchase wood for heating and cooking.

**Economic status:** there are 9 members in Tanveer's family and his older brother with a 10<sup>th</sup> grade education is the only employed person. His monthly income is meager.

**Impact of assistance:** The donor funds have helped but still they need more funds to cover Tanveer's expenses.

### **8.11. Sadia Noor:**

Sadia got paralyzed in the 2005 earthquake when she was in 9<sup>th</sup> grade. She left the hospital two months ago. SCIPPER has sponsored her for the last one year.

**Health status:** Sadia is suffering from multiple problems, like bedsores, UTIs and abdominal problems. She has been operated 9 times. She cannot get some medicines due to financial problems. The funds

provided by SCIPPER are utilized in purchasing catheters and covering the expenses of operations. The wheel chair being provided is not in a good condition.

**Environmental status:** the cold winters are unbearable for Sadia, although she can manage in summers. Moreover the sanitation system needs to be developed in the area.

**Economic status:** there are 6 family members in her family and no one is employed. Their home has two rooms and no bathroom. Her father, Noor Afsar khan is suffering from tremors and is unable to do anything. Sadia wants further assistance to cover her medical expenses. They purchase wood for heating. Sadia wants to continue her studies and she is interested in getting computer skills.

### **8.12. Farida Jan:**

Farida is from Rawalakot, Kashmir. She is 29 years old, divorced and living with her parents. She was in NIHD Islamabad for 3 and half years and got discharged 4 months ago. SCIPPER is assisting her since last year.

**Health status:** Farida is a paraplegic. She does not she has improved. She needs expensive medicines. She has been able to go for a checkup after being discharged. She uses knee-ankle-foot orthoses (K.F.Os). She changes urinary catheters every two months, which cost more than 3000 rupees.

**Environmental status:** Farida suffers from severe legs pain especially in winters. The snow fall exceeds 5-6 feet from December to April. Her family borrows wood from their relatives to use for heating and cooking purposes.

**Economic status:** Farida has three brothers and four sisters, but the oldest brother works as a cook in a motel and is the only one employed in the family. One of her sisters is also suffering from a partial spinal injury and her father, Mir Ahmed Khan has lost his eye sight due to an eye injury. Her other sister, Mehram Jan has her hand injured and is unable to work. The family's monthly income barely covers the food expenses and funds provided by SCIPPER are being utilized for her medicines.

### **8.13. Saira Ismail:**

Saira is 17 years old and is a paraplegic. She is from Haitian, Muzaffarabad. She left the hospital on July 01, 2009 and is now living with her family. She is getting assistance from SCIPPER for the last 8 months.

**Health status:** Saira has undergone leg amputation, and plastic surgery on her back and spinal fixation surgery. She is now suffering from bedsores of first grade and has had one surgery. She has a wheel chair which is in a very poor condition. She goes for periodic checkups.

**Environmental status:** She experiences similar environmental conditions as the other patients.

**Economic status:** Saira has 8 members in her family and no one is employed. Her father, is an imam in the mosque of the area. Her sister, Shaista Bibi is also suffering from a back injury. They buy wood for cooking food and heating in winters. The transport expenses exceed 8000 rupees to take Saira to a hospital in Islamabad. Saira was operated last year at CMH, which cost RS. 100000, and to cover these expenses Mohammad Ismail, Saira's father took a loan. Patient's family want financial support till she improves or she can earn a living because her brother feels that they will not be able to support her after he gets married.

#### **8.14. Kulsoom Bibi:**

Kulsoom is 27 years old and she is from Mansehra. She did her matriculation and was employed as a health worker before the earthquake. She got hospitalized at the Peshawar Paraplegic Centre for 8 months and then at CMH Islamabad for 3 months. Now she is living with her sister's family.

**Health status:** Kulsoom is a paraplegic and got operated upon twice for bedsores. She is taking medicines regularly but her wheel chair is not in a good condition. She is using external catheters. Health unit of RMF-HF is doing her checkups and counseling every 3 months. These days she is suffering from severe abdominal cramps.

**Environmental status:** Kulsoom is facing great difficulty at home to maneuver her wheel chair. The washroom is also not designed according to her need. She owns a piece of land in Mansehra where she is hoping she will have a home.

**Economic status:** Kulsoom's brother in law is a taxi driver and they live in a rental home. Some of her expenses are covered by the donor funds. Before the earthquake she was working as Lady Health Worker. She also stitches very well and some of her work has been sold in the local market. Kulsoom wants to utilize her skills to earn for herself, as she is good at stitching women's clothes.

### **8.15. Amir Shehzad:**

Twenty-two years old Amir is from Nemila, Mansehra. He is paralyzed and got discharged 2 years ago. He completed his 7<sup>th</sup> grade and was employed as a motor mechanic before being hit by the earthquake.

**Health status:** His SCI is #T4-T5. He is using medicines regularly and his wheel chair is broken.

**Economical status:** Amir's family is economically challenged as his father was paralyzed before the earthquake. SCIPPER is assisting Amir since 2006. It covers medicines and transport expenses. They want SCIPPER to help Amir in get a new wheelchair.

### **8.16. Naseema Bibi:**

Naseema, wife of Khan Wali is 27 years old and is a resident of Balakot. Naseema Bibi remained admitted in Peshawar Paraplegic Centre for 2 and a half years, but now is living with her family. She has two children.

**Health status:** Naseema got discharged 1 and half years ago. She developed Grade 1 bed sores during the early stages of her injury and was also operated once. She is now regularly using medicines but taking her to the hospital for checkups is not possible for her husband as there is no one else to help him carry her on a 'charpai'. She is not sure if her situation will improve.

**Environmental status:** The earthquake destroyed their house. They were provided with a temporary shelter, comprising two rooms and a single bathroom. A wheelchair cannot be used in this shelter. Moreover; Naseema also cannot visit a medical facility for medical care regularly due to the highly rough terrain they live in.

**Economic status:** Naseema is being sponsored by a SCIPPER donor for last two years and it is the only source of income for the whole family. Naseema's husband cannot leave their home, as their children are too young to support their mother. Naseema asks if HF can help her husband find employment.

### **8.17. Safia Bibi:**

Safia is 19 and is an inhabitant of Batgram. She was a student of 9<sup>th</sup> grade when the earthquake hit her. She got hospitalized in Peshawar Paraplegic for 1 and half years, and now is living with her family in Batgram. Basheer, Safia's older brother also got paralyzed. Thus their family is having a very hard time as two of their children have become paralyzed.

**Health status:** Safia is suffering from third degree bedsores and has also been operated thrice. According to her father, although she is regularly using medicines, her condition has not improved. A wheelchair has been given to her but she is so weak that she cannot move it by herself. Her parents take her to the hospital after every 2 months.

**Environmental status:** Safia's family use fuel wood for cooking and heating purposes, especially in winters. Abdul Salam, her father is too old to cut and bring wood by himself, thus they need to pay extra money to purchase wood.

**Economic status:** Safia is being sponsored by a SCIPPER donor, for 2 and a half years. Abdul Salam is no more able to earn, and Basheer, Safia's older brother, who was the only person earning to support the family, is also paralyzed. The funds provided by the project are being utilized by both of them. This support is, therefore, not enough to cover all expenses. Their major expense includes medicines and transport. Safia and her brother are taken to Abbottabad for routine checkups every two months and they hire a special vehicle for that, costing Rs. 6000 each time

### **8.18. Noor Jahan:**

Noor Jahan is 33 years old and belongs to Balakot, but residing in Mansehra after her home was destroyed in the earthquake. She got admitted to different hospitals in Lahore and Islamabad i.e. in Sheikh Zaid Lahore, for 6 months, in Lahore Hospital for 4 months and finally in NIH-D Islamabad for 5

months. She got discharged 1 and half years ago and is now living with her family. She also lost her two children in this disaster.

**Health status:** Noor Jahan is quadriplegic (paralyzed below the neck). She developed first-degree bedsores after her injury and got operated upon in Sheikh Zaid hospital Lahore. She has severe back pain. She has been provided with a wheel chair, but is not in a condition to use it. She is taken to the hospital frequently as she is suffering from low blood pressure and kidney infections due to the internal catheters.

**Environmental status:** Noor Jahan's family does not own the shelter they live in and it is not wheel chair friendly. They urgently need a handicap adapted home. They do own a piece of land near the main road In Mansehra, on which a home can be built. The HF strongly recommends that her home be built on a priority basis.

**Economic status:** Hussain, Noor Jahan's husband is a driver and does not earn enough to cover the expenses of his family. The funds provided by SCIPPER are used to provide his wife with medicines. The major expense includes special food and fruits for the patient, medicines and transport expenses. The transport expenses exceed Rs.1000 each time for hiring a special vehicle. Noor Jahan has requested for a special wheel chair meant for a quadraplegic so that she is able to move by herself.

### **8.19. Kaleem-Ullah:**

Twelve years old little Kaleem belongs to village Batangi, Balakot, Mansehra. He was the student of class two, when earthquake hit his mountain home and school. He remained hospitalized in different places i.e. Abbottabad CMH, in a private hospital near Jhallo Lahore, PIMS Islamabad, Chakshehzad and NIH-D, Islamabad. Now with the help of SCIPPER donors, Ms. Jackie and Lisa Ruggerio, Kaleem has been able to continue his studies and has recently completed grade 4..

**Health status:** Kaleem is a paraplegic and injured at level # T10-L2. Kaleem is regularly using medicines, going for routine checkups, counseling and physiotherapy. A wheel chair and knee-ankle-foot orthoses have been provided to him. Kaleem's older brother thinks that Kaleem's condition has improved. He is regularly visiting the PIPOS Centre Balakot for his periodic check ups.

**Environmental status:** Kaleem's family resides in a highly remote area of Balakot, requiring 4 hours of walking on a mountain trek from the main road. The area is rough, and the family faces a lot of difficulty

carrying Kaleem to the main road and hiring a special vehicle for him. However, in winters they have easy access to wood for fuel.

**Economic status:** SCIPPER and RMF are sponsoring Kaleem for the last two years. This provides him with food, transport and educational expenses. Kaleem is getting home education by a village teacher who visits his mountain shelter every day. He has successfully passed grade 2<sup>nd</sup> and 3<sup>rd</sup>.

## **8.20. Mian Rafiq:**

Mian Rafiq is 18 and belongs to Balakot. He was studying in 7<sup>th</sup> grade when hit by the earthquake. Now with the help of Ms. Athena and RMF USA, he has been able to continue his studies and he is in 10<sup>th</sup> grade. Rafiq got discharged from the hospital 1 and half years ago.

**Health status:** Mian Rafiq is a paraplegic and injured at #T12-L1. He suffered from bedsores of third grade and was operated twice. Moreover he also suffered from leg bone fracture and kidney stone when he was hospitalized. A wheel chair has been provided to him and he is regularly taking his medicines. He goes for periodic checkups after every 15 days. Rafiq thinks his condition has improved.

**Environmental status:** Rafiq's family is living in a tent as they lack their own. Also this tent is not a disabled friendly one, thus Rafiq faces a lot of problems, unable to move his wheel chair even within the house.

**Economical status:** SCIPPER and RMF-USA are sponsoring Rafiq since 2006 and this support has covered his medical, educational and transport expenses. He was found in Jabree in a critical condition with deep wounds, fever and bed sores in 2005 and transferred to the Paraplegic Centre Peshawar. He was admitted there for 18 months. Rafiq wants this fund to be continued till he becomes independent and can earn a living. His mother has been provided with a buffalo, by Ms. Athena.

Recently, Hashoo Foundation received 6000 GBP from its UK office to build a home for Mian Rafiq and its construction is expected to start soon.

## **8.21. Anusha:**

Anusha, daughter of Arshad is 7 years old, from Muzaffarabad. She was just 3 years old when she was injured during the earthquake. She remained admitted at the NIH-D Islamabad for 4 years. Parveen Akhter, her grandmother has been her caregiver since then. Anusha's father also got injured during the earthquake.

**Health status:** Anusha is a paraplegic and injured at # T12.L1. She was admit in NIH-D since 2005 and got discharged in July 2009. According to her grandmother Anusha is doing much better and is now able to sit on her knees and take her shoes off by herself.

**Environmental status:** The heat of Islamabad and the unhygienic condition of the hospital made Anusha and her grandmother. They are currently temporarily living in Taxila with their relatives. Anusha's grandmother doesn't want to go back to their tents and hopes to get a simple home which would be suitable for Anusha.

**Economic status:** SCIPPER has sponsored Anusha for the last 2 years. Anusha's parents are no longer supporting her and her grandmother needs this funding to be continued as they have no other source of income. The funds have been used for food, fruits, medicines, catheters, pampers and her clothing. Parveen wants knee-ankle-foot orthoses for Anusha so that she could attempt to take steps with this assistive device.

## **8.22. Mohammad Hussain Awan:**

Hussain, son of Kalander Khan is 26 years old and is has become a paraplegic since the earthquake. He belongs to Muzaffarabad. He lost his wife during the earthquake and has a 6 year old daughter, Salma. He got discharged from the hospital 1 and half years ago and is now living with his family in Muzaffarabad.

**Health status:** Hussain has been left wheel chair-bound and needs a full time attendant. His brother ALI Bahadaer is his full time caregiver. He is paralyzed at #T12.L1.L2. His wheel chair is not functioning. He is suffering from recurrent renal stones. He has already been operated twice on and gets urinary tract infectios. Thus he is not satisfied with his treatment and has asked SCIPPER to help him get proper treatment.

**Environmental status:** Hussain is feeling very uncomfortable with the extreme weather conditions. In winters it becomes difficult for him to cope with the cold weather whereas in summers his bedsores get worse. He suffers a lot while being taken to the hospital due to the rough roads and lack of special vehicle or ambulance in the area.

**Economic status:** Hussain was a mason before the earthquake and used to earn enough to run his family. After the earthquake he was left totally dependent on his brothers. Only one of his brothers is employed as a soldier in the army. SCIPPER has helped cover his basic needs, including his medicines, food, catheters and transport expenses which cost 3000 rupees each time.

### **8.23. Mohammad Ali Butt:**

Mohammad Ali butt is 34 and belongs to Muzaffarabad. He has completed his secondary education and was running a business of electronic appliances. The deadly earthquake left all his business and property abolished. Besides this loses Mr. Butt has learnt to perform most tasks of daily living and he and his wife have also helped other paralyzed patients learn such skills. This has included learning how to shift in bed, how to use the toilet, eat, catheterization techniques, change clothes and how to maintain personal hygiene.

**Health status:** Mr. Butt is a paraplegic with his injury at vertebra level # T10. Mr. Butt, although paralyzed, has learnt how to easily perform his daily tasks. He uses medicines regularly and goes to the hospital for regular checkups once a month. He does his physiotherapy himself. Mr. Butt also worked as a trainer in NIH-D and taught other SCI patients these skills. He was forced to leave when he was critical of the hospital administration and the care provided to the SCI patients.

**Environmental status:** Mr. Butt has been in and out of the hospital. His family has intermittently lived in a rented house in the outskirts of Rawalpindi. Because of a recurrence of bedsores, renal and orthopedic problems, he was recently admitted in Polyclinic hospital. The Butts own a piece of land in Tarnol, Rawalpindi. With the donations a small home has been partially constructed. It needs a boundary wall, electricity and water lines need to be fitted. It has unfortunately, been very difficult to complete a good quality home in a timely manner because of distant location of the land and difficulties in the building process.

**Economic status:** before the earthquake Mrs. Butt was employed as a teacher, and after losing all of their property in the earthquake she has become her husband's caregiver. Currently Mrs. Butt has joined a school as a teacher. Her income however cannot cover their expenses, and the donor support greatly helps. Mr. Butt wants to start a business to move towards complete independence.

#### **8.24. Shaheen Akhter:**

29 years old Shaheen Akhter is a resident of Bagh, Azad Kashmir. She remained admitted at the NIH-D, in Islamabad for three years and now is back with her family in Bagh, where her husband and children are taking care of her. She lost one of her daughters, (Seema Yousaf) in the earthquake and her other daughter fractured her leg and can't walk properly.

**Health status:** Shaheen is a quadriplegic (paralyzed from the neck down) and with the spinal cord injury in the neck at C5.C6. Shaheen is suffering from bed-sores and she has been operated upon thrice for this. She also gets urine infections and uses of internal catheters. She has been given a wheel chair and is visiting the hospital for regular checkups every two months.

**Environmental status:** Shaheen's family does not own a home and are living in a shelter comprising of two rooms and a single bathroom. This shelter is congested and very uncomfortable for Shaheen to live in. A wheelchair also cannot be used there. She also wants help to build a disabled adapted home.

**Economic status:** Shaheen has received SCIPPER donor funds for the last 3 years. This has been the only income for the whole family and helps meet only some of her basic needs. M. Yousaf, her husband is her only caregiver in their shelter and thus has been unable to work. Intermittently, Yousaf borrows money from his brother. Shaheen needs a caregiver, a home and her husband a job.

#### **8.25. Anzar Bibi:**

Anzar belongs to a village near Muzaffarabad. She is 20 and had completed her secondary education when she was injured in the earthquake. She became a quadriplegic and also lost her brother, Sarmad in this disaster. She was hospitalized for 2 and half years at the NIH-D Islamabad and now lives with her parents in Muzaffarabad.

**Health status:** Her spinal cord has been injured at C5 and T1. She is taken for medical checkups periodically. She is very much depressed.

**Environmental status:** Anzar left the hospital because she couldn't tolerate the heat there, nor the monotonous and unhygienic environment of the hospital. She now lives with her family but remains unhappy. She wishes to live in a disabled-friendly home where she would have more comfort and mobility, as compared to her current shelter, where she is in bed the whole day.

**Economical status:** Anzar's family lives in a rented home. Ashraf (Anzar's father) is employed as a laborer and his earnings help cover the food expenses of the family. The funds provided by the SCIPPER donor help cover her medical and transportation needs.

## **8.26. Wahab Jan:**

Twenty five (25) year old Wahab Jan belongs to a village near Muzaffarabad. She was hospitalized in CGH Rawalpindi, Islamabad for 2 years after the earthquake and now she is back with her family.

**Health status:** Wahab Jan is a paraplegic and was injured at level #L2. Her husband gives her physiotherapy and she visits the hospital regularly for routine checkups. Her husband feels that she has improved considerably over time.

**Environmental status:** Wahab Jan is living in a shelter, which does not adequately protect her from the harsh weather conditions. Their tent is 4 km away from main road. She is carried to the road to make the trip to the hospital for her checkups and this journey is very uncomfortable. She also needs a wheel chair friendly home.

**Economic status** Wahab Jan has been receiving donor funds for the last two years. This funds help with her basic needs and to purchase fuel wood for cooking and heating. Wahab Jan would like to receive this assistance till her husband gets a job.

### **8.27. Arshad Bibi:**

Arshad Bibi is 32 years old and belongs to Tariqabad, Kashmir.

**Health status:** After the 2005 earthquake, Arshad Bibi remained hospitalized in Rawalpindi CMH for two years. She became a paraplegic and has chronic bedsores. She has had one surgery for the bedsores. She regularly visits a medical facility and feels that her condition has improved during the last one year. The footrests of her wheelchair have broken and need repair and sitting in it is very uncomfortable.

**Environmental status:**

After leaving the hospital, she lived in a tent with poor ventilation and sanitation. In this paralyzed state, she gave birth to her fourth child in the tent. Her husband stopped working and became her caregiver. For over 2 years she has received monthly donor funds. This has been their only source of income. Her children's education has been covered by these funds, which have also been used for food, medicine and transportation.

Through the tireless efforts of Ms. Tahere Shirazee and Ms. Kamila Jeevanji (cf photo), numerous friends and very generous donors, a home has been built for Arshad Bibi with wheel chair access. It still has some areas that need finishing and improvement. Arshad Bibi and her family, moved into the home a few months ago. It enables her to move herself in her wheel chair in her home and her quality of life has improved since this.

### **8.28. Bushra Bashir:**

Bushra belongs to Muzaffarabad and could not continue her studies after 9<sup>th</sup> class after the earthquake. She is now 22 years old and has been abandoned by her family. She became paralyzed and was admitted in NIH-D Islamabad for one and half years. She left the hospital in 2007 and now living with her uncle's family.

**Health status:** Bushra has chronic urinary symptoms and infections and has been using an internal catheter. Her wheelchair also needs repair. Her uncles home is located in a distant area and she is taken for medical checkups once every four months or so.

**Environmental status:** Bushra lives with her uncle's family. The house she is residing in is not wheelchair friendly and she is unhappy with her immobile situation. She has asked the HF staff to help her find another residence.

**Economic status:** Bushra does not have another source of income and has been receiving donor funds for her immediate needs.

### **8.29. Awais Rehman:**

Awais belongs to village Jabree Balakot, Mansehra, NWFP. Awais Rehman is 16 and got discharged from Peshawar Paraplegic Center 2 years ago. He was studying in 7<sup>th</sup> grade before the earthquake. His condition improved initially and he has been ambulant with a slow gait and this has remained mostly unchanged. He has had back surgery and chronic back pain and although he can walk slowly, Awais has difficulty walking on the rough and rocky terrain. Awais also often suffers from respiratory infections.

**Environmental status:** Awais's family lost all their property in the earthquake. Their relatives have given them a shelter temporarily in Balakot.

**Economic status:** Awais's father has taken a loan of Rs. 400,000/- from a local bank for his back surgery. Awais has been supported for his education from RMF. His grades have been fair and he is in 10<sup>th</sup> grade now. He also receives monthly SCIPPER donor assistance for over 2 years, which is used for his medicines, transport expenses and food.

### **8.30. Rubina Kausar:**

Twenty-two years old Rubina Kausar is a paraplegic and belongs to Muzaffarabad. She got discharged from NIH-D, Islamabad this year and has returned to her village. Rubina lost her mother in the earthquake.

**Health status:** Her injury is at vertebral level # L3 - L5. Rubina is taken for routine checkups every two months. She is medically stable.

**Environmental status:** Rubina's family is living in a temporary shelter, comprising of two rooms and a bathroom. The shelter unhygienic and made of iron sheets, and does not provide adequate protection from the weather. Rubina also needs a clean disabled adapted dwelling.

**Economic status:** Rubina is now doing her F.A with Allama Iqbal Open University and her educational and other expenses are funded by the donor funds of Rs. 6000 per month. Rubina is aiming to get a degree and then work to make a living. She also hopes to have a better home in the future.

### **QUESTIONNAIRE**

**Name of Patient:** \_\_\_\_\_

**Father's / Husband's Name:** \_\_\_\_\_ **Gender:** Male  Female

**Status:** Widow  Orphan  Needy  Other

**Age:** \_\_\_\_\_ **N.I.C :** \_\_\_\_\_

**Contact #:** \_\_\_\_\_

**Residential Address:**

\_\_\_\_\_  
\_\_\_\_\_

**Permanent Address:**

\_\_\_\_\_  
\_\_\_\_\_

**Qualification (before E.Q):** \_\_\_\_\_

**Profession (before E.Q):** \_\_\_\_\_

**Current status of the patient:** hospitalized  discharged

**Getting assistance from:** SCIPPER  any other org

**Period of assistance:** \_\_\_\_\_

**Nature of injury:** \_\_\_\_\_

***Disability***

Paraplegic  Paralyzed  Quadriplegic

***Bed sores***

Operated

**Grades** 1.skin  2. muscles  3.bones

**Details of treatment**

1. Medicines

2. Medical equipments:

Wheel chair  toilet sea   diapers/pads   knee-ankle-foot orthoses foot   
orthoses  HKA locked braced shoes  catheters

**Catheters:**

Internal (abdomen)  Internal (urethra)  External

3. Periodic Checkups

4. Counseling

5. Physiotherapy

**Details of other family members:**

S.No	Name	Age	Gender	Profession/Class	Condition


**Current overall condition of patient:**

Improved

not improved

**Current Social Condition:**

Abandoned

family support

independent

**Is there any side effect or other problem caused during the treatment? Yes  No**

**Are the funds provided enough for the medical and other expenses? Yes  No**

**Are you satisfied with the assistance provided by SCIPPER? Yes  No**

**What is the impact of assistance provided by SCIPPER on your lives?** \_\_\_\_\_

\_\_\_\_\_

**How long will you need further assistance from SCIPPER?**

\_\_\_\_\_

**Any suggestions for SCIPPER?**

\_\_\_\_\_

\_\_\_\_\_